

**Evolving a vocabulary for effective communication with non-speaking
patients in situations of medical emergency / hospital intensive care**

by
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Master of Design
in
Inclusive Design

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Author's declaration

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Abstract

This Major Research Project (MRP) worked on the design of an extended vocabulary for use by individuals who use Augmentative and Alternative Communication (AAC) devices, which would enhance their communication capabilities in medical emergency and hospital intensive care situations. The vocabulary was derived through a study of the communication needs of users in medical situations. Individual and group interviews were conducted with ten participants – four AAC users, two caregivers, two Speech-Language Pathologists and two medical care professionals. Vocabulary suggestions obtained from them were analyzed and organized. The results provide a preliminary vocabulary and recommendations for ways in which communication by non-speaking persons in medical situations could be improved. In the next stage of this research, a hierarchical vocabulary derived from this work will be incorporated into an iPad-based commercial AAC system and its usability will be studied with the same group of users to further refine and revise the vocabulary.

Acknowledgements

This Major Research Project is dedicated to the many persons who are non-speaking whom I've had the privilege of knowing over the years and to all the participants of this study. Thank you for having faith in what I am doing and motivating me by your participation even though, for some, it was difficult to participate. Thank you for your support! I have learnt so much.

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To all my friends in the course - It has been an amazing two-year term with you all. It was an honour to chat, learn, video, present, read and write and spend hours on assignments. Thanks for beings so supportive.

Dedication

To all my students and teachers - words are not enough to express my gratitude. You have been and will continue to be a source of inspiration for my lifelong learning.

To all AAC users - thank you for always teaching me that nothing is impossible. I have learned and gained much more than I actually contributed.

To my husband, Manojit - I would never have imagined myself doing something like this without your trust and confidence in me. Your faith in my ability and your unquestioning confidence in my work have been motivating me over the years. You have always been with me as a guide and support since the beginning of my career. Thanks for being my critique and supporter.

Table of contents

AUTHOR’S DECLARATION	II
ABSTRACT	III
ACKNOWLEDGEMENTS	IV
DEDICATION	V
LIST OF TABLES.....	VII
LIST OF FIGURES.....	VIII
CHAPTER 1 – INTRODUCTION.....	1
CHAPTER 2 – LITERATURE REVIEW.....	3
CHAPTER 3 – METHODS	5
CHAPTER 4 – RESULTS	13
CHAPTER 5 - DISCUSSION.....	25
CHAPTER 6 - CONCLUSIONS AND IMPLICATIONS	27
BIBLIOGRAPHY	29
APPENDIX A: REB APPROVAL LETTER.....	31
APPENDIX B: RECRUITMENT POSTER	32
APPENDIX C1: INVITATION/CONSENT FORM FOR AAC USERS	33
APPENDIX C2: INFORMATION/CONSENT FORM FOR STAKEHOLDERS.....	36
APPENDIX D: INDIVIDUAL INTERVIEW PROTOCOL	39
APPENDIX E: GROUP INTERVIEW PROTOCOL QUESTIONS.....	41

List of Tables

Table 1. Words and sentences used by AAC 1	13
Table 2. Words and sentences used by AAC 2	13
Table 3. Words and sentences used by AAC 3	13
Table 4. Words or sentences found valuable by AAC 4	14
Table 5. Word groupings found useful by non-AAC users	15
Table 6. Important questions and information	17
Table 7. List of 36 words requested more than once.	18
Table 8. Total words requested and their frequency as percentage.	20
Table 9. Alphabetical list of words	21
Table 10. Words arranged in categories.....	23

List of Figures

Figure 1. Picture of AAC device of participant 1	6
Figure 2. Picture of AAC device of participant 2	7
Figure 3. Picture of AAC device of participant 3	8
Figure 4. Picture of AAC device of participant 4	9
Figure 5. Pain scale.	16
Figure 6. Medical history "About Me"	16
Figure 7. Words requested multiple times and their frequency	19
Figure 8. Pie chart of total words requested and their frequency as percentage.....	20

Chapter 1 – Introduction

Communication is vital to human co-existence. This is particularly true in the context of medical intervention, where adequate and effective verbal exchange is essential for patient safety. Communication is compromised when one of the parties is unable to speak, owing to a chronic condition such as cerebral palsy. The objective of this research is to provide the foundation for establishing a vocabulary to engage persons who are non-speaking to communicate more effectively in a medical situation. This study provides the first step in designing a specialized and dedicated Augmentative and Alternative Communication (AAC) vocabulary application for a speech-output device through user needs research.

Three recent studies have examined the consequences of breakdown of communication in situations of medical emergency for persons who are unable to speak. Costello (2000) identified the inability to communicate medical and personal needs effectively as one of the most stressful and frustrating experiences during hospital intensive care. He describes how being unable to communicate is emotionally frightening for children and can lead to medical errors and extended lengths of stay. Costello depicts how the implementation of augmentative and alternative communication (AAC) tools and strategies can address the communication needs of children in pediatric intensive care units (PICU) by enabling them to communicate their wants, needs and feelings to healthcare providers and family members and participate in their own care more productively. He reports that when patient-provider communication improves, treatment success goes up, hospital-caused

errors decrease and patient and family satisfaction improve. Hurtig & Downey, (2008) and Pressman, Pietrzyk & Schneider, (2011) explain the inability to administer proper care in situations of hospital intensive care, unless the medical care professionals are able to accurately assess patient needs. They report how augmentative and alternative communication (AAC) aids and devices facilitate communication with non-speaking individuals, but caution that it can be difficult or time-consuming for the medical care professionals to learn to respond to devices that are unique to the individual user.

Research to date supports the need for an AAC aid with extended vocabulary for medical situations to enable easy and functional communication between medical care professionals and AAC users. This study is based on the investigator's premise that systems designed for AAC users could also help patients who might find themselves temporarily unable to speak due to post-operative or other medical conditions. This premise will need to be investigated in future studies with speaking patients for whom speech has been temporarily compromised. The primary question addressed in this MRP is:

What vocabulary would be useful for medical care professionals and non-speaking patients to communicate effectively in situations of medical emergency or hospital intensive care using an AAC device?

Chapter 2 – Literature Review

This chapter summarizes the background in terms of previous work that led to the research idea of this project. The gap in knowledge that remained to be filled is highlighted. In design terms, a problem is identified in the existing design of AAC devices used by the population being studied, which this project worked on solving by coming up with a more inclusive design.

Generically, Augmentative and Alternative Communication (AAC) refers to all forms of communication other than oral speech (even facial expressions or gestures) that we could use to express our thoughts, needs, etc. Specifically, people with severe speech-language problems, such as those with cerebral palsy, rely on AAC to supplement existing speech or to replace speech that is not functional.

According to Light, Beukelman and Reichle (2003), typically about 8 to 12 people per 1,000 experience severe speech-language impairments and could benefit from AAC. A variety of aids and devices such as picture and symbol communication boards, speech generation devices (SGD) and voice output communication devices (VOCA) are available for AAC. These systems contain vocabularies specially developed and arranged hierarchically so that the users can easily select what they want to convey. Generally, these systems are capable of speaking out the selection using synthesized speech. They usually come with a core vocabulary of essential words, sentences and sentence completions that are commonly used for communication. Extended vocabulary is a term used to specify what is not covered by core vocabulary, which could help in enhancing

communication in not-so-common situations (Beukelman, McGinnis & Morrow, 1991).

In their study, Beukelman, Garrett & Yorkston (2007) acknowledged that most AAC devices do not contain specific vocabulary required for communication in medical situations.

Breakdown of communication in situations of medical emergency can have dire consequences for these individuals according to Costello (2000). In situations of hospital intensive care, unless the medical care professionals are able to accurately assess patient needs, they cannot administer proper care (Hurtig & Downey, 2008; Pressman, Pietrzyk & Schneider, 2011). AAC aids and devices facilitate communication with non-speaking individuals, but these might be difficult or time-consuming for the medical care professionals to learn.

It is in this context that a gap was seen in the vocabulary currently available in popular AAC devices and a need was felt for a vocabulary easily usable not only by AAC users but also by concerned medical professionals and caregivers.

The chapters that follow describe the methods used in deriving such a vocabulary based on a user needs study, the actual assembling of the vocabulary and the implications of this research.

Chapter 3 – Methods

User needs research was conducted with individuals with cerebral palsy who use AAC devices to alleviate speech-language problems. Stakeholders who were non-AAC users, such as caregivers of AAC users, Speech-Language Pathologists (SLPs) and medical care professionals were also consulted. Through analysis of the data gathered, a list of items to be considered for inclusion in a vocabulary was derived for AAC users and hospital staff to communicate with each other in medical situations.

Study Questions

- 1) What vocabulary items persons who use AAC devices feel they need in order to communicate their needs effectively in a medical situation?
- 2) What vocabulary items medical care professionals believe to be important for a non-speaking patient to have available in their communication system to help them understand their patient's needs?
- 3) What is an effective way to communicate using these vocabulary items with a non-speaking patient?

Participants

The research was conducted with a total of ten participants, all of whom were adults and understood English well. Four of the participants were users of AAC devices, two caregivers to AAC users, two SLPs and two medical care professionals familiar with the

care of AAC users or other non-speaking individuals. The AAC users were all adults within the age range of 19 – 50 years. All participants were diagnosed with cerebral palsy and were non-speaking or partially speaking. Of the four users, three were primarily dependent on a low-tech board, comprised of their day-to-day communication. The user who could partially verbalize did not use his AAC device as frequently as the others. The non-AAC users were all adults and professionals with relevant experience in the field. Below are pictures of the AAC users communication board/ device.



Figure 1. Picture of AAC device of participant 1






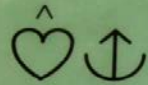














Conversation Starters 	Yes I look up 	I Need my glasses 	No I look down 	Go Forward 
Social Page 	Pronoun Page 	People Pages 	Questions Page 	Strategy Page 
Feelings Page 	Action Words Pages 	Place Pages 	Thing Pages 	"Little" word Pages 
Professional Vocabulary 	Let's stop now 	Let's get some help 	Alphabet & Number Pages 	Time Page 

Figure 2. Picture of AAC device of participant 2

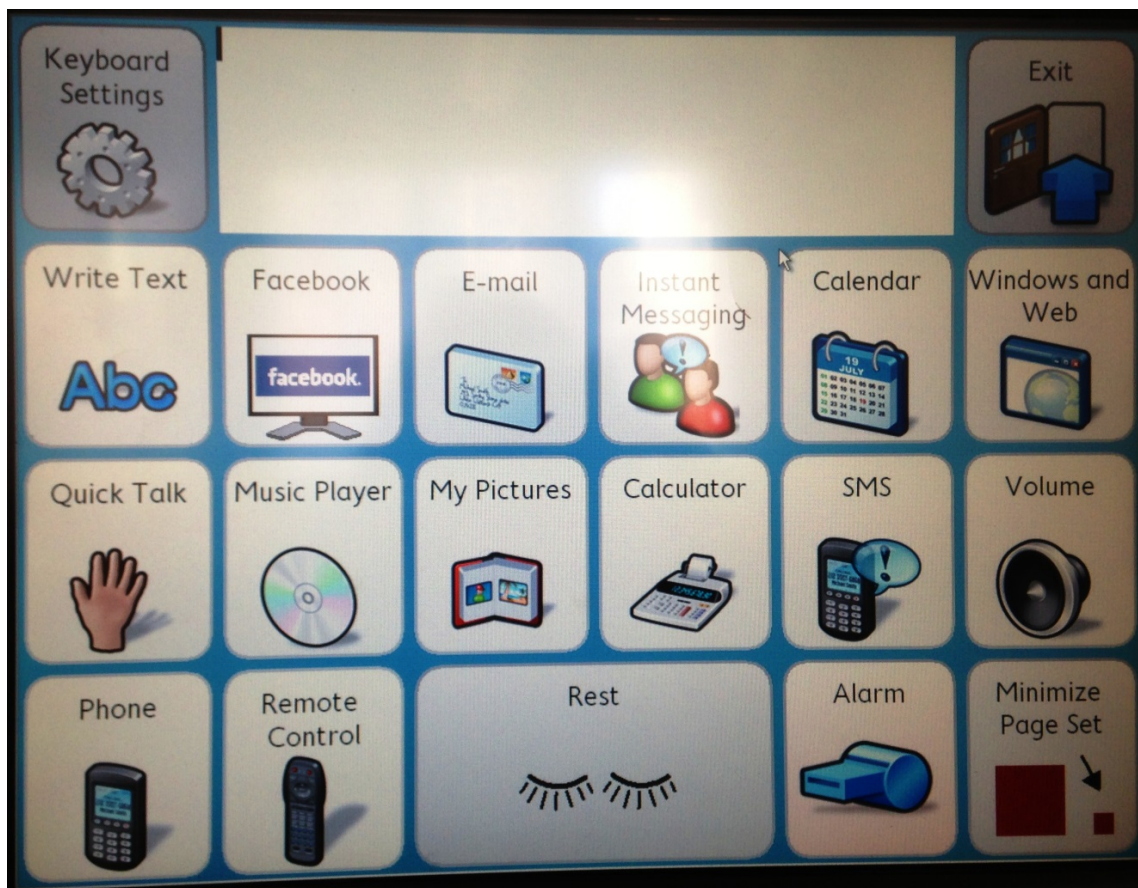


Figure 3. Picture of AAC device of participant 3

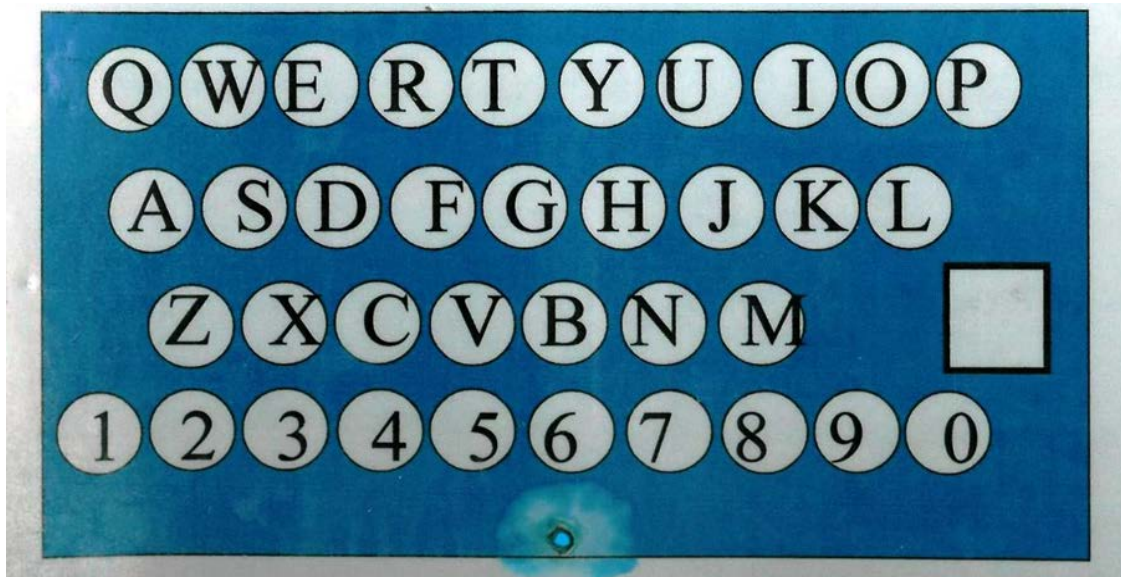


Figure 4. Picture of AAC device of participant 4

Procedure

Participants were recruited with the help of the Ontario Federation for Cerebral Palsy (OFCP – <http://www.ofcp.ca>) who had access to AAC users among their members and partner organizations. Formal support was obtained from OFCP through an email request. A recruitment poster as in **Appendix B**, giving details about the study and with contact information of the investigator, was provided to OFCP and circulated by them among their members.

Upon receiving response from interested participants, the Invitation / Consent form (**Appendix C1/ C2**) was emailed to them and a date and time for interview was confirmed. Participants were informed that they were free to withdraw from the study at any given point of time.

Respondents beyond the required numbers were held on a wait list and were informed that they would be called upon in the event that a participant withdrew during the study.

Participants were then coded as CG1, CG2 for caregivers, SLP1 , SLP2 for speech-language pathologists and MS1, MS2 for medical staff. Participants on wait list were marked WL1, WL2, etc. All data was marked only with these codes; names were not used anywhere during data storage or reporting.

The only personal identifiers collected from participants were the name and email ID. These were linked with participant codes in the participant code file. To ensure confidentiality of data during the conduct of the research, a participant code sheet was created at the time of recruitment. The code file paired the identifying details (name and email ID) of each participant with their code. All data collected, extracted and analyzed referred to the participants using the codes and not their names.

To ensure anonymity and confidentiality in the dissemination of results, participant identities will not be disclosed in reports, and only aggregated or codified / pseudonymized information will be used.

Interviews

Individual interviews with four AAC users and two group interviews with six non-AAC users (two caregivers, two SLPs and two medical care professionals) were conducted.

Individual interviews lasted for about two hours each. All interviews were conducted at the Inclusive Design Research Center (IDRC) in OCAD University, Toronto.

It was explained that as an example of ‘curb-cut advantage’, communication enhancement designed for AAC users through this study could benefit all other Canadians as well in situations when they find themselves rendered non-speaking temporarily due to any medical condition.

Interviews with AAC users were conducted based on the interview guide as in **Appendix D**. Following the guide, each individual was asked questions one by one. Each individual was presented with a rough layout of how the vocabulary would be organized. The subjects were asked to identify words they already had in their book, device, and board which were relevant to a medical setting or an intensive care setting. Each individual was able to produce words they thought important to have and words they had used earlier in similar circumstances. Once participants were able to demonstrate they could successfully produce words they thought helpful in a medical emergency, they were asked to think of words that they would wish to have on a single page or board if the communication aid were dedicated exclusively to medical emergencies. Each participant was able to contribute according to what he or she thought was relevant to the subject. One participant had suggested many questions and additional information that he thought would be helpful on the device.

A group interview was held with non-AAC users where the protocol followed was similar to that used with the AAC users but the questions asked were as in **Appendix E**. No financial compensation was paid to participants for time spent. However, their travel cost was reimbursed where claimed.

At the beginning of each interview, the investigator confirmed with the participant that they have understood the details in the information letter and consent form. Two copies of the consent form were signed by the participant of which one was given to the participant for their personal records. A digital audio recorder to record the proceeding was used during the session only if the participant indicated consent to audio recording in their consent form. All participants gave their written consent to record their interview session. AAC users gave permission to take pictures of their existing communication device. After the interview, the audio file was transferred to the investigator's computer at the University and the file on the recorder was deleted.

From the audio recordings of interview sessions and field notes, relevant data were extracted into an Excel file for analysis. Communication fragments such as words, sentences and sentence completions emerging from this data that were relevant to answering the research question were marked as units of analysis. These units were analyzed and organized to formulate a hierarchical vocabulary module.

Chapter 4 – Results

Each AAC-user participant was able to produce the words and questions they would want to have available to them in a medical situation. Each participant could identify those which they already had on their device or display and / or they had used earlier. The list of words and sentences of users AAC 1, AAC 2 and AAC 3 appear in **Tables 1, 2, and 3** respectively.

Table 1. Words and sentences used by AAC 1

AAC 1						
Words already has/used						
When?	I	little/small	Information	doctor	talk	Sick
Pain	help	I need help in	wheelchair	bed to rest	nurse	Money
Water						

* Information is not a word but it was indicated by the user that it was information about personal medical condition.

Table 2. Words and sentences used by AAC 2

AAC 2						
Words already has/used						
Hospital	Individual names of people who one knows					

* This AAC user used only the names of the people on his board, who in turn would talk on his behalf during a medical appointment or at the hospital.

Table 3. Words and sentences used by AAC 3

AAC 3						
Words already has/used						
my back	my leg	How did my back get scoliosis				

AAC 4, the only participant with the alphabet board, did not cite examples of full words as he was capable of spelling words he needed, depending on the situation. He decided to spend more time on the *kinds* of words and sentences he found valuable to have on a display for immediate use. (Table 4)

Table 4. Words or sentences found valuable by AAC 4

AAC 4							
Body Parts							
body	back	Leg	head	knee	lower/upper	Shoulder	
Questions							
how	why	What	when	where	who	How	
much	how	Many					
New Words							
My name is		I need the washroom please	need	cold	I	friend	Nurse
Can you help me		I am feeling sick.	Like	hot	my	mom	Doctor
I have pain where I am pointing		I am feeling very weak	want	warm	you	dad	therapist
I will point at my numbers to tell you how bad my pain is. 1 is not at all bad 10 is really bad pain.		I am light headed.	Go	sleepy	we	sister	Need
Can you call		I feel better now.	need	tired	they	brother	Like
Can I have a drink of water please		I am very tired	Fall	weak	he/his	wife	Want
Can you repeat what you just said please?		Can I have something to eat please?	Sit	sick	she/her	husband	Go
Can I have an extra pillow please		When is the doctor coming?	eat	upset	our	sister-in-law	Need
Can you put the head of the bed up/down please		Can you help me please	drink	slowly	their	brother-in-law	Fall

Of the three participants who used words rather than spellings all confirmed that their current display lacked appropriate medical terminology.

All non-AAC users described the medical situation as one in which non-speaking persons are vulnerable, lacking in time and opportunity to express fears, concerns and questions.

Rather than citing specific words, non-AAC users focused their responses on the grouping of items and were more concerned about the organizing and layout of the vocabulary which was being discussed.

Table 5 provides the list of groups that the non-AAC users thought would be helpful to have in the display.

Table 5. Word groupings found useful by non-AAC users

List of groups						
About Me...	Question...	Where is my...				
Pain Level...	Body parts...	I can...				
Positioning...	Feelings ...	Medication List...				

All non-AAC users stated the need for an advocate and improved communication methods. They described the lack of *direct* communication with non-speaking patients in medical situation. They expressed the need for a “pain scale” indicator (**Figure 5**),

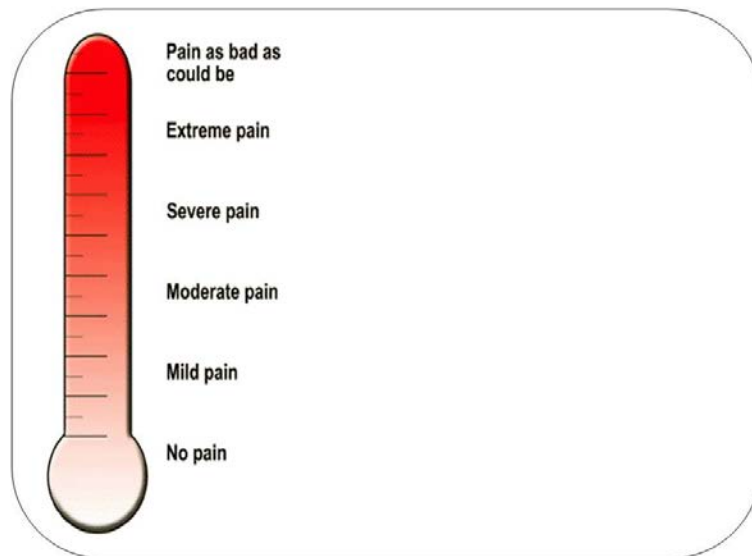


Figure 5. Pain scale.

In addition to the vocabulary items, they requested the addition of a medical history record (**Figure 6**) to be positioned in a location that can be available when needed by the non-speaking patient.

Figure 6. Medical history "About Me"

One participant suggested a list of questions and information to be asked by caregivers or patients (**Table 6**) that could be helpful in a medical situation to administer treatment effectively.

Table 6. Important questions and information

Important question / information for medical professionals			
What medication you are on?	How long has this been going on?	Have you been sick to your stomach?	history of seizure...
list of their medication	When did you last see your doctor?	Did you take your medication today?	Do you have headache?
movement: do you have any restriction in your movement	Have you spoken to your doctor about this?		
Important question / information for AAC user			
what's happening to me	I have something important to tell you...	can't breath	allergies
can't breath	chest pain	can't swallow	what's happening to me
I have something important to tell you...	Drugs: what are the side effects/ is it covered by OHIP	severe headache	I have an invisible medical condition

Based on all the interviews conducted, a total of 215 word *requests* were extracted from the audio recording and the notes. These 215 requests represented 150 *words*. Of these 150 words, 36 were requested more than once and 114 were only requested once. **Table 7** contains the list of 36 words.

Table 7. List of 36 words requested more than once.

Word	Number of times requested
Back	2
Cut	2
Eat	2
Family	2
Go	2
Head	2
Hungry	2
Knee	2
No	2
Nurse	2
Positioning	2
Talk	2
Thirsty	2
Time	2
Tired	2
Yes	2
Cold	3
Drink	3
Help	3
Hot	3
How	3
I	3
Need	3
Sleep	3
Stop	3
Want	3
What	3
Where	3
Who	3

Why	3
Leg	4
Sick	4
Wheelchair	4
When	4
Doctor	5
Pain	6
36 Words	101 requests

They account for 101 requests. These words, that were requested multiple times, are arranged according to the number of times they were requested.

Figure 7 represents a graph of the words requested multiple times and their frequency of occurrence.

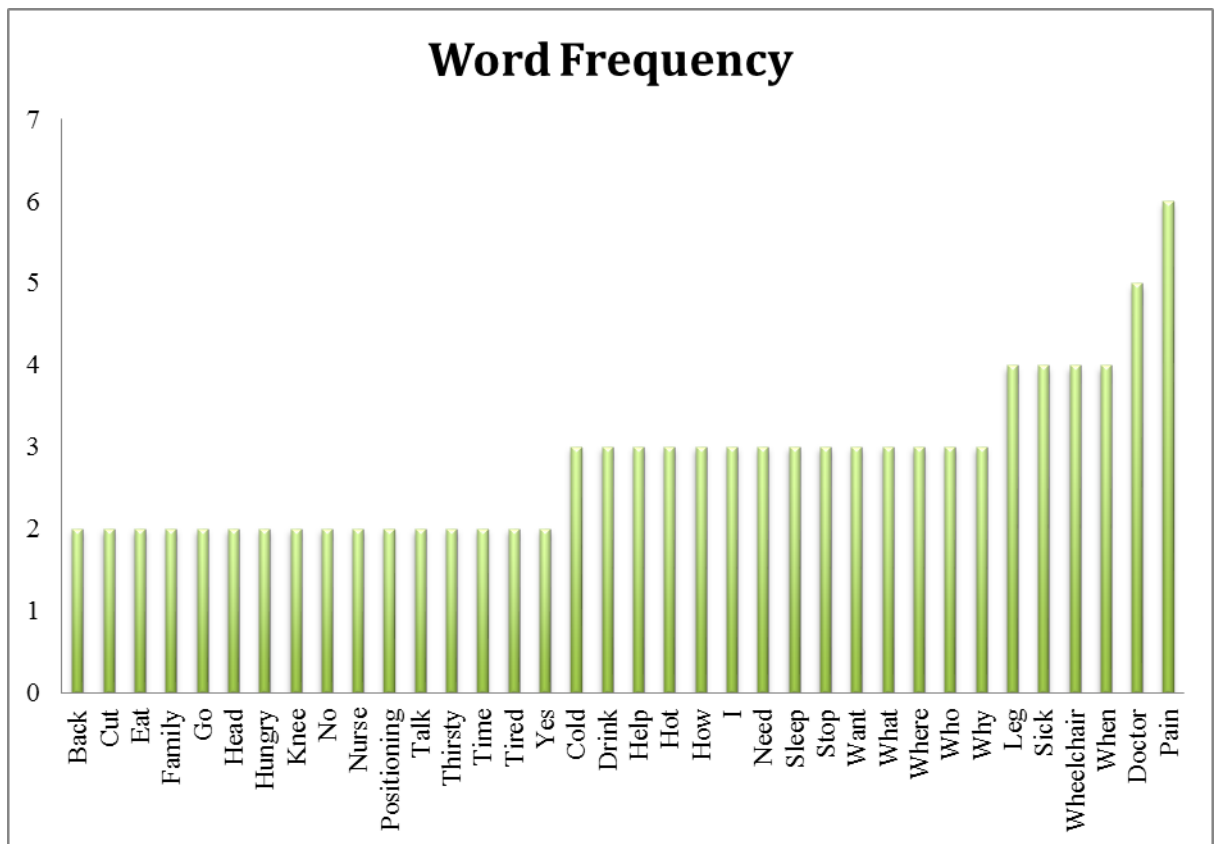


Figure 7. Words requested multiple times and their frequency

Table 8 provides a detailed representation of the total *words* requested (150) and the number of times they were requested along with percentages.

Table 8. Total words requested and their frequency as percentage.

1	114	76.0%	Word used 1 time
2	16	10.7%	Word used 2 times
3	14	9.3%	Word used 3 times
4	4	2.7%	Word used 4 times
5	1	0.7%	Word used 5 times
6	1	0.7%	Word used 6 times
150 words		100%	

Figure 8 provides a pie chart of the total 150 words and the number of times they had been requested.

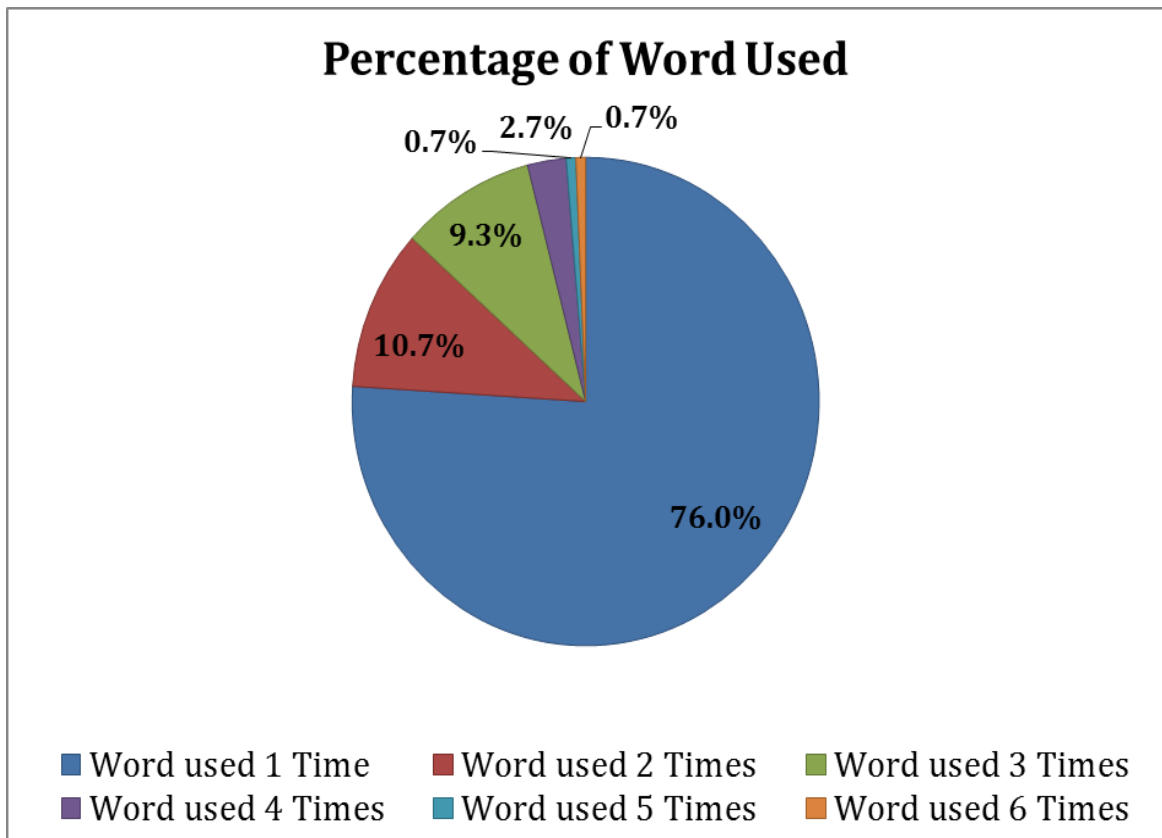


Figure 8. Pie chart of total words requested and their frequency as percentage.

Table 9 represents the total list of words, alphabetically ordered and the categories in which the 150 words and list of questions were organized.

Table 9. Alphabetical list of words

List of words requested once		
About Me	Address	Age
Allergy	Arm	Back
Bed	Blanket	Body
Brother	Brother-in-law	C.P
Care	Catheter	Change
Clean	Close	Cold
Comfort	Cry	Cut
Dad	Dead	Diagnoses
Different	Doctor	Done
Door	Down	Dress
Drink	Ears	Eat
Elevator	Emergency	Eyes
Fall	Family	Fear
Feeling	Finger	Friend
Get	Go	Good
Hand	He	Head
Health Card	Help	Hip
Hospital	Hot	How
How Long	How Much	Hunger
Husband	Hygiene	I
I Have Pain	Information	Knee
Leg	Light	Like
Listen	Living	Location
Lonely	Lower	Many
Me	Medicine	Minister

Mom	Money	Much							
My	Need	Next							
No	Non Speaking	Nurse							
Okay	Open	Our							
Pain	Phone	Positioning							
Priest	Question	Quick							
Relationship	Scoliosis	She							
Shoulder	Show	Sick							
Sister	Sister in law	Sit							
Sleep	Slow	Slowly							
Small	Smart	Stop							
Strategy	Stroke	Suction							
Switch	Talk	Telephone							
Their	Therapist	They							
Think	Thirst	Thirsty							
Throat	Time	Tired							
Toilet	Uncomfortable	Understand							
Up	Upper	Upset							
Visitor	Want	Warm							
List of words requested twice									
Back	Cut	Eat	Go	Head	Hungry	Knee	No		
Positioning	Talk	Thirsty	Time	Tired	Yes	Nurse			
Wash		Bath			Washroom				
Water		We			Weak				
What		Wheelchair			When				
Where		Who			Why				
List of words requested 3 times									
How	I	Need	Sleep	Stop	Want	What	Who	Where	Why
Wife			Yes			You			

List of words requested 4 times			
Leg	Sick	Wheelchair	when
List of words requested 5 times			
Doctor			
List of words requested 6 times			
Pain			

The total words requested were grouped into the following categories: Standard, Family, Body parts, About me, Objects, Medical Diagnosis, Questions, Sentence completion, Miscellaneous and Personal. These lists were some of the suggestions that the participants came up with during the interviews. The words with the highest frequency and high priority in terms of medical situation were grouped as Standard as they were words that could be used by all generically. However, not all words with high frequency were included in this category. Some words with high frequency were included in other category like Body parts, Questions etc. based on where they fitted more meaningfully. Words that were judged by the investigator to be specific to an individual, such as Catheter, Stroke, etc., were listed under Personal.

Table 10. Words arranged in categories.

Standard						
About Me	Care	Change	Cold	Cut	Comfort	Diagnoses
Different	Doctor	Done	Down	Dress	Drink	Eat
Elevator	Emergency	Fall	Fear	Feeling	Get	Go
Good	Help	Hospital	Hot	Hunger	Hygiene	I
Like	Information	Listen	Me	Medicine	My	Need
Non speaking	No	Next	Nurse	Okay	Open	Our
Pain Phone	Quick	Show	Sick	Sit	Sleep	Sleepy

Slow		Slowly	Small	Smart	Stop	Switch	Talk		
Telephone		Therapist	Thirst	Thirsty	Time	Tired	Toilet		
Uncomfortable		Understand	Up	Upper	Upset	Warm	Washroom		
Water		Bath	Weak	Wheelchair	Yes	You	Think		
Family									
Dad	Brother	Brother in law	Family	Husband	Sister	Sister in law	Mom	Wife	
Body Parts									
Arm		Back	Body	Ears	Eyes	Finger	Hand		
Head		Hip	Knee	Leg	Shoulder	Throat			
About me									
Address		Age		Allergy		Health Card			
Object									
Bed		Blanket		Door		Light		Money	
Medical Diagnoses									
C.P		Scoliosis							
Questions									
How		What	When		Where		Who		Why
Sentence Completion									
Clean		Close		How long		How much		I Have Pain	
Positioning		Question		Location		Strategy			
Miscellaneous									
He	Lower	Many	Much	She	Their	They	Want	We	
Personal									
Catheter		Cry	Dead	Friend	Minister		Living	Priest	
Relationship		Stroke	Suction	Visitor	Lonely		Wash		

Chapter 5 - Discussion

It was apparent, throughout the study, that AAC users focused their attention on specific words and sentences that they thought relevant, whereas the non-AAC users or professionals directed their discussion to problems which were present in medical situations. The latter group cited the need for proper training, greater awareness, and AAC users taking control of their own care. They emphasized the lack of time and training on the part of the staff and caregivers.

The limited ability of the AAC user in medical situation was evident from the limitation of the vocabulary on their AAC devices. None had a specific page related to medical care, medical information or emergency words. Some had some words relevant to this subject but they were spread throughout different pages. It became apparent that many AAC users rely on others to help address their communication needs in specific situations. This dependency was reflected in the desire by AAC users to have all information about themselves and contacts handy as part of the vocabulary display structure when developed. While organizing the words as shown in **Table 9**, importance was given to the words that were requested just once. These words were new and most of them were not in the display of the AAC user who made the request. They were unique as they were only requested by one person as relevant words to have on a device for communicating in a medical situation.

Other words, which were requested by more than one participant were organized based on the judgment and experience of the investigator. Those words were placed in different

lists according to categories they fitted best. Words which were more related to talking about or describing a personal situation were not included in the standard list. The standard list was developed so that words which could be used by all and could be used in different context could fall under this category. Short sentences, phrases and sentences were put in the category of sentence completion.

Single words suggestions added up to a total of 114, which is a large number. This has a potential for further organizing and grouping through user feedback so that they could be fitted on a 4X4 display. In such a layout, it would be of immense importance to determine which words should be on the home, or first, page and which would occur in lower hierarchies in the order of usability and importance (especially in cases where the display was printed out and used as a low-tech. backup board).

Chapter 6 - Conclusions and implications

The objective of this project was to design a vocabulary that would enable non-verbal individuals who use Augmentative and Alternative Communication (AAC) devices to communicate their needs in medical emergency and hospital intensive care situations. A vocabulary was derived based on user needs research with some AAC users, caregivers, speech language pathologists and medical care professionals.

This research provides insights into a vocabulary that AAC users and other stakeholders feel important for a medical situation. The value of these findings might be assessed only by testing how they would actually help in a real situation. Further refinements could then be applied to enhance its usability.

Through an Accelerate internship funded by Mitacs Inc¹, between July and December 2013, the investigator will be organizing this vocabulary into a hierarchical module and integrating it with the iPad-based TalkRocket Go² AAC software of MyVoice Inc., who is an ADP-certified vendor of AAC software. User testing of the hierarchical module will be done with the same users who helped the investigator arrive at the vocabulary.

The results of this project might assist others investigators working on improving communication in medical situations. An important consideration for future work is the design. As the vocabulary is designed for patients and medical staff, customizability of

¹ <http://www.mitacs.ca/accelerate/program-guide> (last accessed August 2, 2013).

² <http://myvoiceaac.com/app/talkrocketgo/> (last accessed August 2, 2013).

some of the vocabulary based on the user's ability to access the words would be important.

This product, when incorporated into an iPad has the potential to be applied beyond AAC users. As an example, a patient in the ICU who is temporarily experiencing a loss of speech would be able to use the specialized medical vocabulary to achieve and enjoy the same benefits as AAC users, through a "curb cut effect"³. It is hoped that this study will provide motivation for further investigations providing feedback as to the usefulness of situation-specific vocabulary and layout in the real world as used by real users!

³ Sidewalks redesigned with curb cuts to accommodate wheelchair users, are also useful for people using skateboards, rollerblades, bicycles, shopping carts, and baby strollers. Benefits that occur when developing information products with accessibility in mind are likewise referred to as the "electronic curb-cut effect." <http://www.icdri.org/technology/ecceff.htm> (last accessed May 20, 2013).

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Appendix A: REB Approval Letter



Research Ethics Board

April 19, 2013

Dear Sherly Thankappan,

RE: OCADU 101, “Evolving a system of effective communication with non-speaking patients in medical/emergency/medical care settings.”

The OCAD University Research Ethics Board has reviewed the above-named resubmission. The protocol dated April 19, 2013 and the consent forms dated April 19, 2013 are approved for use for the next 12 months. If the study is expected to continue beyond the expiry date (April 18, 2014) you are responsible for ensuring the study receives re-approval. Your final approval number is **2013-15**. Please note that your clarification regarding cognitive impairments vs. communication difficulties should be noted in any report that you produce. Before proceeding with your project, compliance with other required University approvals/certifications, institutional requirements, or governmental authorizations may be required. It is your responsibility to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the OCAD U REB prior to the initiation of any research.

If, during the course of the research, there are any serious adverse events, changes in the approved protocol or consent form or any new information that must be considered with respect to the study, these should be brought to the immediate attention of the Board. The REB must also be notified of the completion or termination of this study and a final report provided. The template is attached.

Best wishes for the successful completion of your project

Yours sincerely,

A handwritten signature in cursive script, appearing to read 'Tony Kerr'.

Tony Kerr, Chair, OCAD U Research Ethics Board

OCAD U Research Ethics Board: rm 7520c, 205 Richmond Street W, Toronto, ON M5V 1V3
416.977.6000 x474

Appendix B: Recruitment poster

Call for Participation in Research:

- AAC Users
- Medical care professionals
- Speech Language Pathologists and
- Care givers

Your help is needed in a study for

“Evolving a vocabulary for effective communication with non speaking patient in medical emergency/ intensive care setting”

To participate, or for more information please contact before April 17, 2013

Sherly Thankappan, Principal Student Investigator
OCAD University
Inclusive Design Research Centre
205 Richmond Street West (2nd Floor)
Toronto, ON
M5V 1V3



sherlythankappan@yahoo.com

647 893 1549



Appendix C1: Invitation/Consent Form for AAC users

Date: **May 02, 2013**

Project Title: **Evolving a vocabulary for effective communication with non-speaking patients in situations of medical emergency / hospital intensive care**

Principal Student Investigator (PSI):

Sherly Thankappan
Student, Master of Design Program in Inclusive Design
Faculty of Design, OCAD University,
205, Richmond St. W,
Toronto (ON) M5V1V3, Canada.
Phone: (647) 893-1549
Email: sherlythankappan@yahoo.com

Faculty Supervisor:

Prof. Geoffrey Shea
Faculty of Design, OCAD University
205 Richmond St. W., Toronto (ON)
M5V1V3.
Phone:
Email: gshea@faculty.ocadu.ca

INVITATION

Thank you for your interest to participate in my study. I learnt so far in my study that while communication is very critical in situations of medical emergency and hospital intensive care, the vocabulary typically available on AAC devices is not adequate for AAC users to effectively communicate their medical needs and for medical care professionals to respond meaningfully. As an AAC user, you will be able to help me in evolving a vocabulary for this purpose by participating in this study.

WHAT YOU WILL DO

You will spend about two hours in an interview session with me, which will be held at the OCAD University office on Richmond Street, the exact address of which is given above. I am an Ontario Certified special needs teacher and have worked with AAC users. So I am sure we will have a comfortable conversation. We will talk about your AAC device and the terms your device already has for medical situations. I will also ask you to share your experiences in medical emergency or hospital situations or scenarios you could imagine. If you wish, you could prepare a script at home about this and bring it with you on your own portable computer or your device for us to read together. If you need, I could arrange for your computer to get connected to the Internet. I will be audio recording our interview so that I can listen to it later and note down without any errors all that we spoke about. Please let me know if you do not wish your talk to be recorded. There is a space in page 3 of this form for letting me know about that. In that case, I will not record our talk but only take notes of our conversation.

POTENTIAL BENEFITS AND RISKS

There may be no direct benefit to you as a participant in this study. You might, however, derive satisfaction from having helped in the design of a resource that could benefit the AAC user community and medical care professionals to communicate better in medical situations. Participating in the study will not cause any harm to you within my knowledge.

CONFIDENTIALITY

I will be storing the audio recordings of our sessions on my computer very safely and securely. Only I will have access to this information. I will destroy the files from my computer at the end of one year. I will not be using the data for any other research nor sharing it with any other researcher. Your name will not be connected with any of the data or results. I will be creating a code for you and storing all your information under that code.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer one or more questions during the interview. Further, if you wish to withdraw from this study at any time, please let me know. I will then confirm your withdrawal and I destroy the data collected from you till that point. I wish to assure you that by withdrawing you will not be put to any loss of benefits to which you are entitled and you may do so without any penalty.

PUBLICATION OF RESULTS

At the end of the study, a short article about the research outcomes will be written up and submitted to OFCP for posting on their website. I will share a link to this article with you via email.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact me, Sherly Thankappan, (Principal Student Investigator) or Prof. Geoffrey Shea, my Faculty Supervisor, using the contact information provided above. The Research Ethics Board at OCAD University, Toronto, Canada, has reviewed this study and issued ethics clearance (Ref. no. 2013-15). If you have any comments or concerns, please contact the Research Ethics Office through jburns@ocadu.ca or at 416-977-6000 ext.474.

If, after reading and understanding the above, you decide to participate in the study, please fill in the Consent form on page 3 except for the signature and email this document back to me. When we meet, I will obtain your signature on a printed copy of your consent form and also give you a copy to retain with you.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

I agree for audio recording of my session with the researcher to ensure accurate capture of data for further analysis. I am aware that this material will be treated as confidential.

☐ YES ☐ NO, I do not want audio recording of my session

Name: _____

Profile [Tick what is applicable to you]

- ☐ AAC user
- ☐ Caregiver
- ☐ Speech-language pathologist
- ☐ Medical care professional

Signature: _____ Date: _____

Reimbursement of travel expenses

My travel expensed on public transport for attending this interview amount to \$ _____. This amount may please be reimbursed to me.

Received an amount of \$ _____ towards travel expenses on public transport for attending this interview.

Name: _____

Signature: _____ Date: _____

Thank you for your assistance in this study.

Appendix C2: Information/Consent Form for stakeholders

Date: **May 02, 2013**

Project Title: **Evolving a vocabulary for effective communication with non-speaking patients in situations of medical emergency / hospital intensive care**

Principal Student Investigator (PSI):

Sherly Thankappan, Student
Master of Design in Inclusive Design
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205 Richmond St. W., Toronto (ON) M5V1V3.
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Faculty Supervisor:

Prof. Geoffrey Shea
Faculty of Design, OCAD University
205 Richmond St. W., Toronto (ON) M5V1V3.
Phone:
Email: gshea@faculty.ocadu.ca

INVITATION

Thank you for your interest to participate in my study. I learnt so far in my study that while communication is very critical in situations of medical emergency and hospital intensive care, the vocabulary typically available on AAC devices is not adequate for AAC users to effectively communicate their medical needs and for medical care professionals to respond meaningfully. You will be able to help me in evolving a vocabulary for this purpose by participating in this study in your role as a professional who might have dealt with AAC users or non-speaking individuals and sharing your views and experiences.

WHAT YOU WILL DO

You will spend about two hours in a group interview session with me and other professionals. The session will be held at the OCAD University office on Richmond Street, the exact address of which is given above. I will also ask you to share your experiences in medical emergency or hospital situations or scenarios you could imagine. If you wish, you could prepare a script at home about this and bring it with you. If you need, I could arrange for your computer to get connected to the Internet. I will be audio recording our session so that I can listen to it later and note down without any errors all that we spoke about. Please let me know if you do not wish your talk to be recorded. There is a space in page 3 of this form for letting me know about that. In that case, I will not record our talk but only take notes of our conversation.

POTENTIAL BENEFITS AND RISKS

There may be no direct benefit to you as a participant in this study. You might, however, derive satisfaction from having helped in the design of a resource that could benefit the AAC user community and medical care professionals to communicate better in medical situations. Participating in the study will not cause any harm to you within my knowledge.

CONFIDENTIALITY

I will be storing the audio recordings of our sessions on my computer very safely and securely. Only I will have access to this information. I will destroy the files from my computer at the end of one year. I will not be using the data for any other research nor sharing it with any other researcher. Your name will not be connected with any of the data or results. I will be creating a code for you and storing all your information under that code.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer one or more questions during the interview. Further, if you wish to withdraw from this study at any time, please let me know. I will then confirm your withdrawal and I destroy the data collected from you till that point. I wish to assure you that by withdrawing you will not be put to any loss of benefits to which you are entitled and you may do so without any penalty.

PUBLICATION OF RESULTS

At the end of the study, a short article about the research outcomes will be written up and submitted to OFCP for posting on their website. I will share a link to this article with you via email.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact me, Sherly Thankappan, (Principal Student Investigator) or Prof. Geoffrey Shea, my Faculty Supervisor, using the contact information provided above. The Research Ethics Board at OCAD University, Toronto, Canada, has reviewed this study and issued ethics clearance (Ref. no. 2013-15). If you have any comments or concerns, please contact the Research Ethics Office through jburns@ocadu.ca or at 416-977-6000 ext.474.

If, after reading and understanding the above, you decide to participate in the study, please fill in the Consent form on page 3 except for the signature and email this document back to me. When we meet, I will obtain your signature on a printed copy of your consent form and also give you a copy to retain with you.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

I agree for audio recording of my session with the researcher to ensure accurate capture of data for further analysis. I am aware that this material will be treated as confidential.

☐ YES

☐ NO, I do not want audio recording of my session

Name: _____

Profile [Tick what is applicable to you]

☐ AAC user

☐ Caregiver

☐ Speech-language pathologist

☐ Medical care professional

Signature: _____ Date: _____

Reimbursement of travel expenses

My travel expensed on public transport for attending this interview amount to \$ _____. This amount may please be reimbursed to me.

Received an amount of \$ _____ towards travel expenses on public transport for attending this interview.

Name: _____

Signature: _____ Date: _____

Thank you for your assistance in this study.

Appendix D: Individual interview protocol

Before the session

- Participant consent form was printed out.
- Participant numbers and session date were filled out on the form and in the protocol document.

Start of session

- Confirmed from the participant that he/she had read and understood the Information/Consent material. If not, it was read out and explained.
- Participant's signature was obtained on the Consent Forms.
- If the participant did not want recording, then the recorder was set aside and notes taken.
- Else the recorder was started and the following information was announced.
 - Participant number:
 - Date:
 - Session start time:

Initial conversation with the participant

Thank you for helping me with my study. Let me assure you that your participation is voluntary. If you feel uncomfortable with any part of the session or any of the questions, you may skip it. You are also free to withdraw from this study at any time. There will be no negative consequences.

Prompted with these questions and probed deeper on each one

1. Could you please tell me about the terms on your AAC device that you have used so far in medical situations?
2. Could you show me the words that may describe specific conditions or need in that context?
3. Could you tell me about a medical situation where you felt satisfied with the way communication went?
4. Could you tell me about a medical situation where you felt dissatisfied with the way communication went?

Discussion of structure

The layout of the planned vocabulary structure was shown on paper. The plan for structuring the vocabulary in an easy way with individual items, full sentences and sentence completion and organizing it into grids was explained to them.

Vocabulary could consist of:

1. Questions
2. Relaying information and
3. Urgent information

Scenario-based questions

1. Recall an experience you had in a medical situation and think of the words you needed in each category:
2. Look up the words you have on your device that are related to health information. For each one, say whether it is specific or can be used in a number of settings?
3. Imagine that you are going to the hospital. What are the words you would need to make you feel confident to communicate with a medical care professional without any family interpreting or help?

End of session

- Do you have any other comments or questions?
- Can I contact you later in case any clarification or follow-up becomes necessary?
- Thank you very much for your participation.
- Note session end time:
- Turn off the recorder. Check recording.
- Transfer data file to computer; store securely; delete file from recorder

Appendix E: Group interview protocol questions

Prompted with these questions and probed deeper on each one

5. Please tell me about your association/experience with AAC users.
6. Please tell me about your experience with AAC users in a medical situation, If any.
7. Could you tell me about a medical situation where you felt satisfied with the way communication went?
8. Could you tell me about a medical situation where you felt dissatisfied with the way communication went?
9. What, according to your experience, are the gaps in the vocabulary for such situations?

Scenario-based questions

4. Recall an experience you had in a medical situation and think of the words you might have needed on the AAC device of the user in each category:
5. Imagine yourself in the hospital. What are the words you would need on the AAC device of the user to make you feel confident to communicate with them when they do not have any family interpreting or help?